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ABSTRACT

This article presents an argument for reforming Australian public policy in favor of social care, rather than family, residential, or community care, for the elderly, sick, and disabled. After noting policy assumptions that families are the focus of caring and women are the natural caregivers, the paper describes changes in Australian family structures that militate in favor of policy reform. Trends related to marriage and childbearing, women in the labor force, family incomes, the aging population, legislation, and employment practices are analyzed. The paper then considers the impact of financial cutbacks on community care. The terminology of "care" and "caring" is analyzed, and hidden assumptions and connotations of this terminology are discussed. The paper then provides estimates of the numbers of Australians with particular needs for care and offers evidence that women are the main caregivers for children, the disabled, and the elderly. Discussion then turns to the caring role, covering such topics as the caregivers' need for specialized knowledge and instrumental and emotional support; stress levels; the hierarchy of public support; and research needs. Costs of care are considered next, with an emphasis on the indirect social costs of the enormous contributions that families are required to make to care provision. Next, Australia's Home and Community Care (HACC) program, the main funding source for caregiver support, is described, and a care plan linking HACC agencies with informal sources of care is suggested. New directions for care are recommended with respect to community support for caregivers, housing, research needs, empowerment, employer roles, and new family roles. Finally, a social caring model that would ensure nationwide availability of adequate public services is outlined. (AC)

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Sharing

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the Caring

Rethinking Current Policies

Christine is 51, and well established in a public service career. Her parents are 81, and becoming frail, less able to cope. Her only sister is raising two children alone (her own are grown and gone), and also works full-time. Whilst their parents are able, by careful management, to pay for a house-cleaner and jobbing gardener, they are having increasing difficulty managing day to day chores, including shopping and cooking. The parents badly need a holiday. They are very proud, and do not want Christine to buy assistance for them. She visits regularly, has them for the day at weekends, and worries about their health and ability to cope. She has just been offered a new job opportunity which will inevitably mean longer hours.

Brian is 42. He has two children at school. His wife has become progressively ill, has had to give up her part-time job, and barely manages the home and family, with assistance. Her prognosis is not good, and although her parents try to help they are themselves ageing. Brian's family lives overseas. Brian is considering giving up his own job to care for the family, but this would entail a long-term spell on benefits and probably mean the loss of the family home. At his age, he feels he would be unlikely to get back into the workforce. His employer is sympathetic, but the increasing frequency of time off for medical visits or to assist at home is affecting his work, and his colleagues.

Alan is 68 and retired. His wife is also failing and he is her devoted carer. Their income is limited, but he has accessed support services and has joined a self-help group. He has learned to cook, but has home-help to clean. He knows several other men who are caring for spouses.

Jean is 68. She worked part-time until she was 60 and then retired with her husband, who is a few years older. She had no superannuation, and their joint income is largely his super supplemented by benefits. She raised a daughter who has married and has a child with a severe disability. The daughter lives nearby and Jean helps daily, while her daughter tries to complete some studies. She is finding the competing



This paper by Dr Don Edgar, Director of the Australian Institute of Family Studies, was commissioned by the Office of Women's Interests Perth, Western Australia, and published there with the assistance of the Office of the Family. It is reproduced in *Family Matters* to encourage a wider response to the issue of caring.

demands of her husband, who wants her to share his retirement more fully, and her daughter and grandchild, difficult to manage, but she feels she should be able to keep

everyone happy. She is very tired, and her doctor has told her she should learn to take it easy.

Carol, Jean's daughter, is 34. She is aware of her mother's difficulties, and is struggling to complete a course which will give her better job opportunities and income. If she gave up her course and part-time work and stayed home the caring role would become entirely hers. Her husband is supportive, but works long hours to get the overtime, and travels to the city each day. Carol feels trapped, and guilty. She is determined to improve her own situation in the belief that this offers the best future for her family.

These are just a few examples of the lives of millions of families who cope, one way or another, with their caring role.

The expectations placed upon the women, and indeed their own expectations of themselves, are different from those of the men. This is not because the men care less, but because the situation of the women is influenced by their socialisation, their economic situation, and their own skills and experience. If you doubt this is so, try changing the genders of our examples.

If Brian were in need of full-time care, his wife's part-time occupation would not have supported the family. She would probably be at home with him, running the home, and on benefit.

Jean's retired husband is not expected to assist regularly with the grandchild. He thinks the child's mother should be home all the time. If the roles were reversed, Jean would be complaining about not having his company. He would be trying to maintain the housekeeping and cooking to keep her happy.

Christine probably would feel less guilty and pressured if she had been born and raised as 'Christopher'. Almost certainly her parents' expectations would be different. They would be grateful when he cleared the gutters and mowed the lawn.

Because we are first cared for and first learn to care about others within a family context, and because dominant views of appropriate sex roles are reinforced in so many ways, it is difficult to break through the policy assumptions that flow from that experience. Families become the accepted focus of caring and women are seen as the 'natural' carers.

When it is asserted that the family is 'the basic group unit of society', 'the most important welfare system of society', we may forget that no family really survives alone, especially in a modern and complex industrialised society such as our own. We may forget too that families can be oppressive and violent rather than happy little systems of care and cooperation.

Such catch-phrases have a ring of truth but capture only a partial reality. For in every culture throughout human history family units have joined together in larger households, tribes, clans, communities in order to produce and care for one another. There have always been others who care, who take responsibility or whose actions at least have an impact on what families do and how they operate.

Underpinning all forms of social organisation are the two main 'tasks' and preoccupations of life — the necessity to survive, via some form of productive activity, whether that be hunting, gathering or working for wages; and the necessity to be social, to care for, and be cared for by, others. At the extremes of social/economic organisation are the so-called 'free market' where every individual or group pursues self-interest to achieve those ends, and full State control where choices are subsumed under some definition of the common goal (Pusey 1991).

Families operate very differently under variants of those extreme economic systems. Family units are essentially systems of cooperation and negotiation (which will often involve conflict and competition) where people combine their resources and talents, act jointly to maximise their wellbeing and distribute (often very unequally) both the costs and benefits of their joint action (Edgar 1992; Wolfe 1989).

Families are also the focal point for sexual behaviour and thus the seeding ground for socially-produced gender differences in learned competence, power and role expectations. The biology of child-bearing is translated into an ideology of motherhood and assumptions about the caring role which are sustained and reinforced by the division of labour in society. We have constructed a society in which the main burden of care has been placed on women, the burden of earning an income on men, a division which makes 'natural' what is only one way of handling those key human tasks. That structure is changing and so must the nature of caring itself.

Glendon (1989) suggested we are facing unprecedented change in 'the three pillars of economic security and social standing for every individual'. The family, the State and the market have each, separately and together, acted as crucial sources of support for economic security in modern societies. The three work as a 'package' of support, with a different 'mix' at different stages of the life cycle, the family remaining the most crucial source of security for dependent individuals at every stage. Because the family is so central as the major carer, the dependency-self-sufficiency balance is most vulnerable when changes occur in family structure.

But we need to examine clearly the extent to which the public purse and other social institutions provide adequate support for families to carry out that caring responsibility. Indeed, we need to ask what are the limits of care that can sensibly be carried by families themselves.

Our starting point has to be that caring is *not* just a burden or a problem, or a cost to private time and public revenue. Rather, it is central to the human condition and rests upon our essential *inter-dependency* and the inevitable caring *about* other people that arises from our close relationships with them. This is as much true of men as it is for women, though we seem to have forgotten those underlying reciprocities.

The social bonds that are central to every 'workable' society are currently under strain. Freedom involves 'choice', and those social bonds must be supported by government policy or there is no choice. Caregiving is everybody's business, not just the business of women. Nor is it just the business of families, a point made very clear by the growing dissatisfaction with rigid work structures still premised on a notion of family life and divided roles that is manifestly out of touch with today's reality. Child care is not a women's issue; it is a meeting point between caring responsibilities and our obligations to productivity and the economy. So too, increasingly, is aged care and our approach to integrating youth, people with physical and intellectual disabilities into a productive and caring society.

The purpose of this discussion paper is, therefore, to suggest some rethinking of current policies about the caring tasks and how we share them. Such a re-examination has implications for the links between home and work, housing and public transport, education and health programs. It will require a much more insightful economic analysis of the long-term costs of current approaches which puts social policy on an equal footing with economic policy.

Australian Family Structures and Pressures for Change

Several demographic and social trends have to be faced squarely by planners, politicians and service providers if caring tasks are to be handled more sensibly.

Marriage and children

Marriage is no longer universal (as it almost was in the 1950s and 1960s); it comes later (average age in 1990 for males was 26.4, for females 24.3); and it is less likely to survive 'until death do us part' (divorce rate rose from 2.9 per 1000 in the 1950s to 36.1 in the 1990s). Such changes complicate any easy assumptions about who will care for whom, at what stages of the life cycle.

Children come later (average age at first birth for women rose from 23.6 in the late 1950s to 28.3 in the 1990s); there are fewer children per marriage and they cost more to raise. The number of families with only one or two children reduces the potential number of carers later in the life cycle. Nevertheless, some 61 per cent of children are still raised in families with two or more siblings (McDonald 1990); 82 per cent of children live in intact, couple families; and 12 per cent live in one-parent families. Extended education plus changes in the youth labour market keep them dependent on parental support for longer. Thus many families caring for

the aged will still have caring responsibilities for older children and the burden of care will grow.

Women in the labour force

Better education, higher costs of living, the desire for economic independence and sources of fulfilment outside family life, have led to the major change affecting the structures of care — the higher labour force participation of women. This obviously challenges the notion that someone is always at home to care for dependents, of whatever age or need.

In the 1950s barely 20 per cent of women and only 13 per cent of married women were in paid work. Since 1986 women in the labour force have risen from 47.9 per cent to 52.2 per cent in the first half of 1991. Numbers in full-time work declined from 64 per cent in 1986 to 60 per cent in 1991, with 40 per cent in part-time work averaging 15 hours per week. Women comprise 76 per cent of the part-time workforce.

The increasing participation of married women with children is of special significance (Maas 1990:60-61). In 1991 some 42 per cent of working women and 40 per cent of working men had children. Young (1990:36) also reports that the average woman's working life has increased from 18.2 years in 1946 to 25.6 years in 1986. The Women's Bureau reports that married males and females in the paid workforce have young children in high proportions.

	Youngest child under 5	Youngest child between 5-9
Males	96.5%	Males 93.2%
Females	47.6%	Females 70.0%

(Source: DEET-IDC report on 'Women and Unemployment', October 1991, p.5)

The overall picture of family types in Australia is no longer then the full-time breadwinner/full-time housewife that dominated two decades ago. That 'traditional' family now makes up only 16.6 per cent of all families and 31.6 per cent of all families with dependent children (Kilmartin 1990:58). Now, 15.2 per cent of families are sole-parent families, 86 per cent of them headed by women, with 65.3 per cent of them in the lowest 40 per cent of the family income distribution (Cass 1990:20).

Family incomes

Wage differentials still make males the key 'breadwinners'. Occupational segregation, women's preferences, the lack of paid maternity leave for some 80 per cent of employed women (Glezer 1988), and the still inadequate provision of non-parental child care make for large numbers of part-time 'paid workers/unpaid carers'. But the time available for caring tasks is incontrovertibly reduced. The 'double-burden' for women is a problem being faced by families, but is often ignored by employers, schools and support service structures still operating on outdated notions of how families function.

Another consequence of these trends is that the pool of women not in full-time paid employment to act as volunteers in the community providing care and services is reduced. As well, willingness to accept an unpaid role of this type is eroded.

It should be remembered that Australia's 330,000 one-parent families are mostly headed by women whose incomes are usually below the poverty line and who may also be caring for parents as well as children. The 715,000 'traditional' family housewives also spread across the age range and may have caring responsibilities for spouses and parents as well as children. Not all of them can become volunteers either.

If anyone doubts that women need to earn an income, the latest ABS figures are instructive. While public polls show Australians believe the smallest amount a family of four needs 'to keep in health and live decently' is \$441 a week in the city and \$409 in the country, one in four adult full-time employees earns less than that. Forty-six per cent of workers earn less than \$440 per week, 57 per cent less than \$500. Men dominate the upper income levels, with 60 per cent of full-time women workers earning less than \$500 per week and 27 per cent less than \$400 per week. Despite family allowances and other government benefits, it is not surprising that Australian families need to earn two incomes (ABS, *Newcastle Herald* 30 November 1991).

All the above trends are dramatically affected by the current Australian recession. By November 1991, seasonally unadjusted unemployment stood at 817,500. It continues to increase. For our purposes, the most significant statistics relate to families.

- The steepest increase in unemployment has been among married men. In November 1989, only 93,700 husbands were out of work. Two years later, about 222,000 were unemployed, over half having been without a job for six months or more.
- Virtually all the increase has been among former full-time workers, two-thirds of whom are men. The bulk of these are aged between 20 and 54, 'working-class men in the prime of their working years, half of them married' (*The Age*, 28 January 1992, ABS figures).
- Part-time work, typically the province of married women, has been less seriously affected. There is underemployment and discouragement to register as part of the labour force, but these changes too have implications for the nature of caring in society. Men are more likely to be in the house, but to what extent do they share with the caring tasks?

A recent German study reported that nine out of ten couples where the male was a 'house-husband' were divorced within five years (*The Age*, 26 January 1992), and Russell's studies (1987) of Australian 'new age men' suggests they are not long stayers. This of course reflects the patriarchal division of labour, the devaluation of 'home' work and its lack of recognition in national economic statistics (Waring 1988; Ironmonger 1989), and the continuing gender-based approaches to childhood socialisation and education.

Ageing of the population

The 'ageing' of Australia's population will also have consequences for caring, in both an economic and social policy sense. By the year 2031, Australia's population is projected to be 26 million, with an average age of 42 (now 31), and one in five will be older than 60 (as compared with 15.5 per cent now) (NPC 1991).

The projection that Australia's population of working age (15 to 64) will decline from 66.9 per cent in 1990 to between 60.7 per cent and 64.7 per cent in 2031, with the number of people aged 80-plus doubling from 0.4 million in 1990 to between 1 and 1.5 million, has given rise to concerns about the 'dependency ratio'. It is pointed out that the 75-plus age group (only 4 per cent of the population) already accounts for 28 per cent of total health outlays.

But this alarmist view must be challenged. It assumes that our elders are a burden rather than considering the possibility that we could restructure work and other institutions so their experience and talents could be used as a resource (Edgar 1991b). It fails to take into account likely improvements in labour productivity, the increasing labour force participation of women, and the decreasing numbers of dependent children (EPAC 1990). And it ignores the demographic projection that the rise in numbers of people over 60 will level off in the middle of the next century to stabilise at around 25 per cent (NPC 1991). Australia's most recent National Population Council report is not alarmist, and our care policies should not be premised on a negative notion of ageing and the rising cost of 'dependency'.

Legislative change

Legislative support for gender equity reflects the gradual change in community attitudes about male/female roles. It is not necessary here to review our equal opportunity legislation. But two recent items are of importance to the caring debate. The first is the Industrial Relations Commission's 1990 ruling on parental leave which made it possible for men to share time off to care for newborn children.

The second is Australia's ratification of several International Labour Organisation conventions. ILO 156 on Workers with Family Responsibilities was signed in March 1990 and came into force in March 1991. This requires governments to ensure that all workers (men and women) enjoy job conditions that support rather than interfere with their obligations to children and other family members. A recent Australian report proposes treating 'family responsibilities' along with sex and marital status as grounds for cases against employer discrimination. Australia also ratified CEDAW (UN Convention on the Elimination of All Forms of Discrimination Against Women) in 1983, but entered a reservation against Article 11.2(b), on the basis of the cost to the private sector of paid maternity leave. We had however ratified in 1975 the International Covenant on Economic, Social and Cultural Rights which provides for paid leave or adequate social security benefits after childbirth.

Employment practices

Employers in Australia have been slow to recognise the cost-benefits of more flexible, family-related work practices, but several leading-edge companies now do so and there is a flurry of conference and consultancy activity. Several major companies such as Shell, IBM, Lend Lease, National Mutual, Kodak and ALCOA have declared themselves to be 'family-friendly' and are tailoring work benefits and conditions to suit the family responsibilities of their employees (Wolcott 1991; Carmody 1991; AIFS 1991).

Western Australia's particular situation poses slightly dif-

ferent problems in that companies do not necessarily carry these projects through to regional establishments, though Sigma Pharmaceuticals is building a work-based childcare centre. Most employment in Western Australia is with smaller companies. Nevertheless, some indications can be found. Helen Creed of the WA Miscellaneous Workers Union used her Women's Fellowship grant to explore initiatives in America, and the Office of the Family is seeking to research the practices of small employers in relation to workers with family responsibilities. The WA public sector is also well ahead with its planning for Enterprise Bargaining (DOPLAR 1992), an area where negotiation for flexibility and family-friendly policies could have considerable impact.

Employees will require much more than the provision of work-based child care. The truly 'family-friendly' workplace provides support which ranges from job-sharing and flexitime, to computerised information on aged care, marriage counselling, drug and alcohol advice, to very simple things such as a 'warm-line' which permits parents to telephone between 3-4 pm to check that children have been picked up from child care or are safely home from school. Productivity increases and reduced absenteeism are clear cost-benefits of such approaches, so both altruism and 'best business practice' principles are satisfied. Employers may well be scared off by compulsory legislation proposals but enterprise-based agreements and the growing evidence that both men and women are feeling workfamily stress (Edgar and Glezer 1992) and demanding change means that the private sector will play a greater and greater part in society's 'care' programs, both for children and the aged.

Sceptics of such measures are not only employers who see the family life of their workers as irrelevant to company needs; they are also those who detect an implicit assumption that, with a few 'family-friendly' palliatives, women can still carry the burden of care as well as earning income outside the home. As Edgar and Glezer (1992) argue, full equality cannot be achieved unless major changes occur in the structures of work and caring which might bring about a shift in the ideologies that impose double burdens on women.

The Effects of Change on Women

So far, these social changes have largely affected women because their paid work roles are still seen as secondary to those of men and because 'gender-insensitivity' (Eichler 1988) permeates the discussion of caring.

But there are signs of change on the part of men as well as women (Edgar and Glezer 1992) and clear calls for change from women's groups.

Women in most states have been indicating clearly to Government that these demographic and social changes require a major shift in the direction of policy and programs. Women's Advisory Councils in WA and Tasmania have provided detailed reports from consultations, and New South Wales is targeting the needs of particular ethnic groups.

A Women Carers' Seminar held very recently through the Older Women's Network (The Duty of Care, March 1992) opened its report with the statement 'I don't want to be a carer!'.

The National Women's Health Strategy, developed after

extensive consultation around Australia, identifies the impact of caring on women's health as one of its major issues.

Just as care of children and adults with disabilities can become hidden in the private world of family care, so too does care of the elderly. Child care as such is currently a very public policy issue, but caring for the elderly, whether that be from outside their own home, having them live with you or visiting a hostel will soon take over the debate.

The European Foundation for the Improvement of Living and Working Conditions (1991) reports that the average (female) carer now spends 16 years looking after children but 17 years supporting parents. In the United Kingdom, it is estimated there are 3.5 million women caring for older people that is, twice the number of mothers of children under the age of five! As already indicated, Australia's 'ageing' is less dramatic and subject to fluctuations in migration policy, but: 'Just as choice in full-time child care is now considered a desirable option . . . a similar choice should be available in other care responsibilities. In other words, caring about someone does not necessarily mean caring for them' (Ungerson 1987).

Thus, both demographic changes and the stories that emerge from consultation with women themselves, are indicating that the face of family life has changed markedly in recent decades and caring assumptions from the 1950s and 1960s can no longer be applied. To caring for children has been added caring for the elderly. For those with disabled family members as well, the need for support from outside the family is even more acute. The family unit itself has a different profile, a different time schedule and different priorities for its members, so can no longer be seen as the sole location of caring responsibilities. The varied needs of carers have yet to be properly defined and new forms of community involvement in the caring role have to be developed.

The Language of Community Care

We have to be careful about the terms used in this discussion.

The caring role has always been assigned to women rather than men, sustained by the ideology of motherhood and the gender-based division of labour in society. As the recent Older Women's Network (OWN) report (1992) points out, the terms 'carer' and 'community care' are policy document terms rather than those used in everyday language. 'Prior to the adoption of this convenient terminology, we used to call people who undertook the unpaid care of others, mothers and wives, or daughters and granddaughters, or women friends and nieces . . . and to a lesser extent, husbands, fathers, sons and grandsons . . . such care is not a new concept' (OWN 1992:4).

Indeed, there has been a conceptual slide from individual women as carers to 'family' or 'home' care, to 'community' care in the sense of displacing those cared for out of institutions. The high cost of institutional care led to more emphasis on foster care, hostels for the elderly and home care with support services (Parker 1985). The problem is that those support services are not always available to carers in need.

It is to be applauded that governments have ceased to regard the frail and disabled as inmates for life in institutions. The emphasis has shifted to support for people continuing in

their own homes and funds to provide a network of services throughout the community. But, as the OWN (1992) report suggests: 'the new directions for home-based care have not been without cost ... an unfortunate tendency, when cost restraints begin to bite, for community services to put the needs of people without carers ahead of anyone else in the queue for support and to regard the needs of the carer as of lesser import.'

Australia has followed Thatcher's UK and Reagan's US determination to carve back 'the welfare state'. In fact, Australia never was a welfare state in any broad sense, adopting early in its short history some examples of enlightened welfare support but in the context of a minimal safety net framework. In the last decade, we have followed the Western trend towards targeted, income and/or assets tested benefits rather than preventive support systems or universal entitlement when special needs arise. Our welfare policies have tended to be residual, paternalistic in tone, and relying heavily on the work of non-government services. There has been little understanding of the cost-benefits of prevention, the increasing degree of unacceptable intervention and cost as we move along the continuum from positive support, education and prevention towards crisis management once things have gone badly astray (Edgar 1990:26).

Ironically, the liberalisation of social attitudes of the 1960s and 1970s which brought so much benefit to women, youth, the disabled and to ethnic minority groups, was co-opted by the later political agenda of financial restraint and so-called economic rationalism (Cass 1983; Bryson and Bittman 1988; Baldock 1983; Reiger 1991). The excesses of inadequate care in institutions were obvious. The denial of rights to the intellectually handicapped, people with disabilities, and to people in old age homes was exposed and had to be rectified. 'De-institutionalisation' became the solution, 'equal rights', 'participation' and 'community care' the catch-cries. But the currency soon wore thin when it became clear that governments were using it as an excuse to reduce public expenditure on care and support services.

In practice, the term 'community care' means not care by the community within community structures, but care by women within the family unit. As someone once put it, 'home is the place where, when you have nowhere else to go, they have to let you in'. Governments have traded on the rhetoric of independence, family obligations, community-based care to drive those unable to care for themselves back into the private world of the family and the already-overburdened care of women. In Western Australia 43.4 per cent of HACC clients live alone, rather than in their families' homes, but adult offspring (usually female) carry much of the caring load through visiting, shopping, housekeeping and taking to the doctor.

The discussion also lumps together aspects of community care such as self-help groups, informal networks, neighbours, volunteers, into what is called the 'informal sector', when in fact the individuals (usually female spouses or daughters), who care for the aged and disabled hardly represent a 'sector' with any substance at all. Their circumstances and needs vary enormously; they are often so privatised that no group interests can be effectively expressed; the voluntary and service nature of their work obscures its value to the wider community; and community

organisations that do try to represent their interests are looked at askance if they become too militant. Public policy must recognise the diversity in both the burden and the needs of caring families.

The danger here is of course the assumption that women will and should continue to provide care and that the public role is merely to provide some relief from the stress of caring. Much 'relief' is inevitably only emergency and temporary in nature, whereas what is needed is ongoing help and support. The WA consultations reveal how important is access to reliable respite care and much more needs to be done along these lines.

The language of care also confuses caring about people (the love aspect) with caring for them, which is work. When it is said the mother is the 'natural' caregiver both senses of the word caring are confused, with unfortunate consequences for women, such as pressure to do the caring work and guilt feelings if they do not. The 'gender insensitivity' (Eichler 1988) of discussions about 'family' or 'community' care ignores both the differential impact on the sexes and differences within gender as well.

The shock (and stimulation of serious discussion) caused by one woman's statement at a Sydney conference for carers in October 1991 — 'I don't want to be a carer!' — is testimony to the power of language when hidden assumptions are exposed. Not all women want to care and certainly not all can provide care in the way most often expected.

It is too often assumed that caring is supposed to be done on an altruistic basis. Public support may be in the form of out-of-pocket expenses, or minor service support, but the notion is firmly embedded that paying a wage for the work of caring itself would be inappropriate and may attract the 'wrong' kind of people. This is in direct contrast to the perspective used in the paid labour force where it is assumed that one must pay good wages in order to attract the best people.

Even the terms used in the discussion of models of care reveal the hidden assumption about private versus public responsibility. A 'caregiver' refers to the family member, usually female, who assumes primary responsibility for the day to day tending and support needed by dependent adults. In other words, the labour is given. On the other hand 'care providers' is the term used to describe those who are paid to deliver specific services. This division obscures the fact that caring is central to keeping the whole human enterprise going, because caring appears to be invisible in the organisation of our daily lives. Nor is there any recognition that caring takes place throughout the life course and is central to the maintenance of society. It is not simply a matter of caring for dependents but of sustaining individuals as whole persons in a caring community.

The concept of community care should imply a collective responsibility for protecting the welfare of vulnerable groups in our society and in supporting those whose lot it is to bear a particularly heavy burden of care. But this is at odds with current assumptions about the private family, a market-based economy, and an increasingly non-interventionist approach to government.

Commonwealth and State government expenditures have been declining since the mid-1980s — a retreat from collective responsibility for the welfare of vulnerable groups.

Social Security and welfare expenditure, for example, has declined from 9 per cent of GDP to 7.6 per cent in 1990.

There is thus a clear disjunction between the high-sounding rhetoric of 'community care' and the realities of funding as well as who finally carries the burden of well-intentioned but poorly supported de-institutionalisation programs.

The Extent of Care Needs in Australia

Our central argument is that caring for one another is part and parcel of the human condition. It thus is, and should be, shared and not necessarily seen as a cost or burden imposed by some groups on the rest of the community.

Nonetheless, special needs require special arrangements and some people do require extra care at times of real dependency. The following sketches briefly the extent of caring needed in Australia:

- Some 1,965,000 households comprise families with dependent children (52.3 per cent of all Australian families). Of these, 15.2 per cent are one-parent families. This is a major caring task in itself.
- In 2,153,953 households there are members who are aged over 60, as well as younger family members.
- There are 1,031,100 people aged 70 or over who live in households (as opposed to institutions).
- 485,813 households contain one person aged 60-plus living alone.
- Estimates of the numbers of elderly people with dementia range from 117,200 to 136,300 in 1991, expected to rise by 2006 to between 173,300 to 194,200 (Jorm and Henderson 1986, quoted in *Aged Care Reform Strategy, Mid-Term Review*, AGPS, 1991).
- The rate of Alzheimer's disease doubles for every 4.5 years of age and an increase of 100 per cent in dementia cases is expected by the year 2011 (AIH 1990, p.220).
- The numbers of ethnic, 'old-old' is growing, with some 12 non-English-speaking birthplace groups having over 10,000 at ages 60 and over. Italian aged numbered 88,700 in 1981 (AIMA 1983:226) and there are more than 20,000 each from Germany, Poland and the Netherlands (Aged Care Reform Strategy:137). Waves of migrants from different origins turning age 75 will peak in different years in the next century (p.139). As Schultz and Schultz (1991) point out, the expectations of ageing, overseas-born parents often create a severe burden on their Australian-born, middle-aged daughters whose life styles are far removed from the country of origin. Lack of siblings, language difficulties and the lack of bilingual services reduce access and usage for these ethnic elders.
- The ABS Disability and Handicap Survey 1988 (Cat. No. 412.0.0), defined a disabled person as a person who had one or more than one impairment or a disability that had lasted, or was likely to last, for six months or more (including wearing glasses).

On this definition, in 1988, 2,543,100 people, or 16 per cent of the Australian population, were disabled. Of these, 2,120,600 were also handicapped, and 657,500 were classified as severely handicapped. Some 2,376,900 disabled

people live in households, 116,100 live in health establishments; 1,432,600 disabled people, aged five years and over, living in households, needed help with at least one activity, and 96 per cent did receive help. Most of the increase since 1981 in severe handicap was in the group aged 85 and over.

- From available health statistics we can say that there are other care situations that are also not given recognition in most public programs. For example:

In 1986, there were 25,260 casualty accidents in Australia. In that year, injuries were the leading cause of hospital admissions (29,179), accounting for 10 per cent of all admissions (AIH 1990:42).

The National HIV/AIDS strategy estimates that about 15,000 Australians are infected.

The hospital admission rate (per 1000 population) for 1986 was 186.9 for males and 241.6 for females. Now that rapid hospital bed turnover is the favoured policy these numbers have clear consequences for family care. 2714 children were born suffering severe congenital malformation.

- At 30 June 1991, the Department of Social Security paid 334,000 Invalid Pensions, 94,000 Wife Pensions, 5500 Carer Pensions and 28,200 Other Disability Payments.
- Statistics on the Federal Government's Home and Community Care program (HACC) show that in 1990-91 \$278.9m was spent on people in need of care. HACC services cover basic maintenance and support services to frail aged and younger disabled persons, and to the carers of those persons.

Altogether this adds up to a pervasive and very varied need for care in the Australian community.

Women Are the Main Carers

Lest there be any continuing delusions about who does most of the caring work in Australian society, let us look briefly at the evidence.

Unfortunately, the 'evidence' is less than adequate for our purposes and certainly less than adequate for planning policies and support programs.

The Australian Census asks nothing about family members outside the household unit. Nor do the regular ABS income surveys ask questions about income transfers between income units or across households. So we have a very incomplete idea of the pattern of caring for others beyond the immediate home. We can say some things at least to give an indication of the extent of caring needed:

Child care

Women are clearly the main carers of dependent children. Most mothers express a preference to stay at home and care for their babies in the early stages of life (Glezer 1988) and breastfeeding is seen as an essential component of child health (WHO 1986). But the need for two incomes, and changing value orientations have seen increasing numbers returning to the paid labour force. In 1991, some 14 per cent of mothers with children aged 0-4 years were in full-time work, with 26 per cent in part-time jobs. For mothers whose children were aged 5-14 years, the figures were 29 per cent full-time and 34 per cent part-time. Australian Institute of

Family Studies research shows that despite growing assistance from fathers, the responsibility for child care still falls largely on mothers.

When we look at non-parental child care work, we find again it is the job of women, not of men, whether paid or informal care by relatives, friends and neighbours (Ochiltree and Greenblat 1991). These child-carers in turn have their own family care arrangements to make as well.

Special needs care

In an ABS Survey (1988) of severely handicapped people, one-third had no carer living with them. The remaining 337,800 severely handicapped people had 322,600 carers living with them. But this ABS survey again reflects the inadequacy of rigid survey techniques, because it defined 'carer' as only 'a main helper who lives with the handicapped person' and only asked a few questions about who cared for the other 182,500.

- Women predominated in the carer role. That is, 64 per cent of the 'live-in' helpers were female, mostly women in the 30-44 years age group. Sixty-one per cent of all carers were the spouse of the handicapped person; 21 per cent were parents caring for a handicapped son or daughter; and 11.7 per cent were daughters caring for a handicapped parent.
- In the oldest age groups, there were more male carers than female carers aged 70 years or more, but this is a function of the 'live in' definition of carer used.
- Whereas nine out of ten severely handicapped people aged 516 years had a live-in carer, only 46 per cent of those aged 75 or more did. Ninety-two per cent of those caring for children were the mother; from age 30 upwards it was the spouse; but sons and daughters provided 38 per cent of the care to the oldest age group (over 75 years). Some 205,300 carers were females compared with 117,300 male carers.

This survey did ask who were the 'most common' providers of help thus broadening the picture of who carries the caring task. Spouse/partner was the main helper, but it was daughters who were most likely to give informal help from outside the household. This was mainly with transport, housework and physical mobility. The most common type of formal help was privately arranged or commercially provided home maintenance or home help. The picture that emerges is overwhelmingly one of informal, private help rather than of formal welfare services.

Elder care

Several Australian studies have looked at who cares for the elderly. Kendig (1986), Day (1985) and others find consistently that senior citizens fiercely maintain their independence as long as possible. But that independence is supported by offspring (usually female) who visit, collect, drive, shop and clean for their elders on top of their caring for spouses, children, dependent youth. Brody (1981) in the United States first called this phenomenon 'the woman in the middle' and Schlesinger (1991) describes them as 'the sandwich generation'.

In the AIFS Australian Family Formation longitudinal study, 1500 people aged between 18-34 in 1981 and between 28-

44 in 1991 were asked about the help they give to and receive from their older parents. Glezer (1991) reports that large proportions of this generation offer help and support of some kind to their older parents. It was reciprocated by the elders in several ways, indicating that even those 'cared for' are at the same time resources for and carers of the younger generations. The grandmother as babysitter is still not a ghost from the past.

The Caring Role

Caring takes place on a variety of levels; one does not have to be totally 'dependent' to need assistance. Indeed most care is of this more casual, sporadic kind, yet social policies can ignore the pressures such chores impose on caring families, and workplace inflexibility is a cause of both stress and absenteeism that is unproductive for all concerned (Glezer 1992).

A more useful typology of the caring role that should be applied in research to discover the real needs of carers in Australia is that suggested by Traustadottir (1991) in a study of gender, disability and family life. She points out first that 'caring for' someone is a very general, ill-defined descriptor. Particularly where a child or adult is disabled, 'the caring work often requires specialised knowledge and techniques that are usually associated with professional work, not housework or traditional "mothering" work'.

Some mothers take on an 'extended' caring role, becoming advocates for change in a wider community sense, while others (carers living in poverty in particular) have to treat caring as one part of life as they struggle for survival. Some combine caring with a job or career, others find the caring task too time-consuming and forsake paid work.

Another distinction can be made between caring as an 'empowering' experience, a source of identity and pride, compared with 'caring as disrupting' where women do not see themselves as natural caregivers but do the work because it is the 'right' or the 'only' thing to do in their circumstances. Obviously the impact of caring will differ with the nature of the task and the carer's own perceptions of its value.

British evidence (Parker 1985; Twigg, Atkin and Perring 1990) suggests that daughters and daughters-in-law are usually the principal carers, not men; that husbands rarely give direct help to wives who are carers; that mothers with disabled children get little help; that women carers are more likely to give up jobs. Yet a quarter of fathers report that their work is adversely affected by prolonged family care. Other research (Hoyert and Seltzer 1992) suggests that a spouse caring full-time finds the job more burdensome and stressful than daughters who are able to spend some time on other work or outside activities.

Stress levels associated with special caring tasks include the degree of disability, the carer's own poor health, the degree of night time disturbance, dependency or 'wandering' (called stress 'exacerbators'), while typical stress 'ameliorators' include having work outside the home, adequate housing arrangements, holidays and times away, and level of satisfaction with the help offered (not necessarily given) by others. Australian consultations which brought about the National Women's Health Policy identified the health of carers as one of the major issues. In policy

terms, any lack of support for the carers is likely to create medium or longer-term costs through hospitalisation of the client, or even of the carer herself.

Visits from home helps and community nurses are seen as important but day care for the person cared for, in psychogeriatric hospitals or hostels does not always help, because it involves extra work in preparation and travel (Wells, Jorm, Jordan and Lefroy 1990). As Schultz and Schultz (1991) point out: 'The nature of support that carers need requires closer attention. The needs which carers in the dozens of Caring for Family Caregiver groups which we have been involved in over the past three years have repeatedly identified are not only for instrumental support, such as more flexible and more suitable respite care, but, more importantly, the need for psychological/emotional support. Carers speak of the need for recognition from the community for the service and the work they are doing. They report a strong sense of isolation, and frequently of powerlessness to change their situation. They ask for help in dealing with the many emotional/psychological/social/spiritual issues that are part of their lives and are found to be so draining on their reserves ... Day care opportunities for respite may be inadequate precisely because they fail to address the inner world of the carer, their major concerns such as loss and grief, guilt, anger and resentment.'

There seems to be a hierarchy of public support for the carer:

- The very disabled who live with married children are least likely of all to get help.
- The more they have others living with them, the fewer services are offered.
- Home help is provided more to male carers than female carers who are assumed to be more competent (often without proper investigation).
- Cash benefit rules disfranchise all married women carers.
- Domiciliary and day care services seem allocated on criteria which discriminate against informal carers. They usually see the dependent person as the client and so the carer's needs are rarely taken into account. The HACC program however does target carers and in WA there has been in recent years a significant expansion of in-home and centre-based respite care.

The British research shows that support services are designed to prevent or delay admission to residential care, but they do this by preventing carers 'giving up' rather than by providing what carers actually want. 'Given finite resources, service providers have chosen to support those people who have no one else to help them. It has been suggested that this is not, in fact, the most sensible use of services with some groups of dependent people and that resources might better be directed towards supporting informal carers' (Parker 1985:89).

The Australian research on carers is not very extensive. What is clear, however, is that the oft-repeated view that 'the family no longer cares for its own' is a misconception. Evidence of the strengths of intergenerational support, the predominance of families rather than professionals in the provision of health and social services, the strenuous family

efforts to avoid institutional placement of the old and the central role played by families in caring for the disabled elderly give the lie to that view (Kendig 1986; Day 1985; d'Abbs 1991). Only a tiny minority of the elderly are in residential care. The majority of the old living alone are not neglected by their families. Indeed, the new modified extended family cares for longer than ever before across the life cycle.

This discussion of who does the caring suggests an urgent need for better research. We need much more refined analyses of how women, men, children and families manage to juggle/organise their varied care responsibilities and of its impact on their individual and group wellbeing. Obviously care of an alert but frail elder will be very different from caring for a victim of Alzheimer's disease; care of a disabled child takes on new dimensions as that child grows into youth and adulthood. The impact of an individual's intellectual handicap may be very different in a large or small, a rich or poor family. And the customs, structures and family processes of care will vary widely among ethnic groups and the Aboriginal and Torres Strait Islander communities.

The Costs of Care

The assumption that community care is cheaper than institutional care is in itself poorly researched and we need better baseline figures on the relative costs and benefits of different forms of care. Costs have been shifted from the Commonwealth to State and local government, to the voluntary sector and from there to the family itself. The cost of care to families is largely hidden and we need to recognise the enormous contribution families currently make to care. Indeed without families government expenditure would be much larger. As Rosenman (1991:5) puts it, the key to community care is usually not the services provided by government-funded agencies, but the availability of another person to care for those in need.

As for the United Kingdom, Australian policy works from the strange assumption that public funding should be targeted at those who live alone. The assumption is that if they are living with relatives that family will provide the necessary care and means-testing is applied. Yet the figures for Australia show that of a total number of 258,600 severely handicapped people aged 60 and over, only 27.5 per cent are living alone, and some 187,400 are living with other people. Of this latter group 48,000 have no carer as such living with them, yet publicly-funded home help is not provided for carers who live elsewhere.

It is also important to realise the indirect costs to society of this huge level of unpaid care. Rosenman documents those costs and points out the need for greater appreciation of the value to society of the emotional and caring work done within the family context. She says: 'The reality is that most carers are women and the issue of opportunity costs of time becomes clouded by the issue of the alternative uses of time for women, the wages that they earn in the labour market and the patterns of the female work and family cycle. Taking on caring for an aged family member reflects the pattern of adult life for many Australian women. Their lives phase from caring for children into caring for other family members, into caring for a retired husband with little time in

between for their own employment, let alone a career.'

Income foregone by women means contributions foregone through the tax system and lost production. Inflexible work arrangements for employed people with family care responsibilities mean hidden costs in lower productivity, absenteeism, poor morale as well as the delayed costs of stress, ill-health, and marriage breakdown. On the other hand the cost of informal caring work and its value to the national economy is ignored in economic figures (Ironmonger 1989).

Unpaid work at home has been viewed as being outside the bounds of both social welfare and income security policy. Within social security, the carer's pension is poorly publicised and not linked to the phasing of women into labour market programs. The domiciliary nursing care benefit is only \$1095 per annum compared with the Commonwealth nursing home subsidy of \$35,000 per annum per person cared for. Our taxation system gives no recognition of caring costs, and there is no policy regarding the reasonable dimensions and expectations of informal care and the appropriate role of government in supporting care at home. Rosenman argues that caring should be rewarded, not penalised, and support for the caring role 'should be based upon an articulated family policy in relationship to what we can reasonably expect families to do for one another, and what the limits are' (see also Foster and Kendig 1987).

As Brown (OWN 1992) points out: 'Caring is an economic trap for women. There is no financial security gained by caring and it undermines any opportunity for paid work, for superannuation, for a pension you can live on.' Especially for women without a partner, ceasing work can mean a savage drop in income and a lower standard of living. Superannuation as the favoured policy may well leave women carers behind. 'Having possibly foregone the early repayment of their mortgage, and interrupted a career, they may then face a retirement on the pension without the cushioning effect of a pension'.

The workforce participation rates of women aged 50 and over (that is, those in the peak caring age group) is currently very low, but as younger women with stronger career orientations move into that age group, more will continue to work and fewer will be at home to carry the burden of care. The 'Catch 22' of the social and community services is that improvement in the wages and working conditions for the predominantly female workforce rebound upon the predominantly female users of such services in the form of higher charges or reduced services.

'In a humane society, such as ours claims to be, the principle of justice might well be applied to alleviating the disproportionate care burden carried by some on account of accident, disease, or genetic abnormality affecting a member of their family. Even the economic rationalists fail to recognise the enormous cost-saving to the State because of the caregiving provided gratis by family members. Clarke (1991) claims that carers in Great Britain save the country between 15 and 24 billion pounds a year. In Australia, institutionalised care costs some \$35,000 annually per person, whereas a caregiver may qualify for a mere \$1000 per year in providing a spouse or a parent with the constant care necessary to enable that person to remain at home'. (Schultz and Schultz 1991)

Expanding the HACC Program

The main Australian funding provision for carer support is known as the Home and Community Care Program (HACC). The unfortunate acronym might well be better changed to something like CARE (to stand for 'Care and Resource Effort') but in practice is delivered through local groups using a variety of names.

The HACC program was announced in 1985 to bring together four pre-existing programs (home care, paramedical services, delivered meals and home nursing) under one cost-shared arrangement with the States. Its unique focus was on carers, requiring that assistance be directed to the carers of the frail aged and younger disabled (Staples 1990:4) through respite services and support groups for carers. Special attention is given to ethno-specific and co-located services in remote and rural areas. Western Australia has led the way in providing both in-home and centre-based respite care, funding carer groups for mutual support and a Carers' Open Line to offer advice and support at times of particular stress.

In 1989-90, the combined Commonwealth/State provision was \$411 million. Some \$22m was allocated to respite services and there were 200 ethno-specific services. A third of the Commonwealth spending was directed to rural and remote areas and more 'co-located' services are being developed. The provision of \$71m in unmatched moneys was aimed at encouraging community options and brokerage packages designed to help keep people out of institutional care (Staples 1990). However, as Ozanne (1990) points out, there are still widely differing provisions State by State, suspicion of centralised policy control, and an urgent need to increase take-up both of funds and services.

The HACC program has not been without its critics, though its value as a crucial support system for both carers and the cared-for must be stressed.

Some critics (Howe, Ozanne and Selby Smith 1990; Fine and Graham 1989) hold that the current HACC program is 'very much a "top-down" concept, understood best by politicians and bureaucrats, and least by those who use, or should be using, services offered by the program ... its somewhat unfortunate acronym HACC, has poor "market penetration" and a low level of recognition' (Lee 1990:255).

There is also an inherent problem in the division of responsibility. Policy development is basically a Federal responsibility. Funding is shared between Commonwealth and State governments. Administration is a State responsibility, and service delivery a non-profit and family responsibility. Conflicts exist between the Commonwealth's wish to curtail the growth of nursing homes and the States' incentive to shift older people out of hospitals funded by block grants into those nursing homes or cost shared community services. Another anomaly is that providers get a greater subsidy for a residential place than for community services (\$300-\$400 per week compared with \$30 per week). As Ozanne (1990:21) puts it: 'The 1980s have witnessed major efforts at restructuring the "home or social care industry" by the drawing together of a variety of different programs under the one administration. To this stage, however, it might be claimed that this has been an administrative, top-down exercise, and has not yet had a major impact at the front

line. We have got more, and a wider mix of services, but we are not sure that we are more effective with them!

Coleman (1990:25) puts it even more bluntly: 'Australian social policy discussion still tends to be obsessed by descriptions of total service cost and of organisational structure. It displays relatively less interest in client outcomes and comparative unit costs of various methods for delivering care.'

Graycar and Jamrozik (1989) suggest that policy development is out of touch with the realities of service delivery. The voluntary sector remains fragmented and uncoordinated, and there is a tendency to fund services rather than the individuals needing care. What this means is that women who are the main carers increasingly have to become managers of bureaucratic networks able to find their way through the maze of professionalised services if they are to receive any support at all.

The HACC Review (1988) recognised these failings, calling for more visible and accessible entry points to the care system, assessment of needs with the care user and assisting the individual and his/her family to choose the most appropriate combination of services. Emerging models under examination were the 'lead agency' model (where key care agencies already in an area take on the role of assessment and case management); and the 'community options brokerage model'. This allocates a sum of money to a 'broker' who links services and can buy an array of services for individual clients.

But as Lee (1990:258) points out, these focus on 'coordination' between existing services, rather than on developing a proper *care plan* which links HACC agencies with other informal sources of care including self care. Lee proposed an ideal model which would allow for:

- requests for care assessment from any source — self, friends, family, professionals (the WA Community Options approach now accepts self-referrals and referrals from a variety of other sources);
- independent and trained assessors *not* part of a service delivery agency;
- the case coordinator role goes beyond assessment to arrange actual service provision, the need for home helps, assessing the family's capacity to care and other sources of help;
- comprehensive home help provided as an entitlement;
- assessment of the *care plan*, not the client, would be monitored.

This notion of a care plan designed to muster various resources and maximise independence would seem preferable to top-down 'fitting' of those in need into pre-determined and not necessarily appropriate forms of care. A focus on fitting varied resources to particular care needs might be more attractive to those in need, moving away from the dependency-driven 'provision of care' to people in need, and towards a better integration of self-help, family and friends as sources of help, finding 'resources' in the community other than 'services' as such to build a more caring society.

New Directions for Care

What follows from the preceding discussion presents some real dilemmas. It also suggests some exciting possibilities for a more caring society.

The first dilemma is the ingrained roles of men and women and how far they can be changed. The key question to be asked over and over again is this: 'If caring is so important, why don't more men do more of it?'. Since the answer is, so often, 'Women are the natural carers, men are the protectors and providers', we must ask further: What protection do men have to do nowadays? How much time does it occupy anyhow? And what's 'natural' about staying at home beyond breastfeeding stage, even the school years, to care for a house and a husband who's rarely there? It may be natural that women bear children and breastfeed them, but we all have parents who age, so why does that burden fall on women rather than men? Since so many women today also 'provide' through paid labour, the male provider role can no longer be seen as 'natural' and exclusive, as indeed it never was.

A second answer to why women care suggests another dilemma. It is pointed out that men earn more than women, so 'naturally' they will 'work' while women care. Caring is not seen as work, not valued in economic terms, so the argument is circular; and there's nothing 'natural' about job opportunities and wage structures, they are entirely 'man-made'. So the dilemma is how to redefine work so that it includes caring for dependent others, which is given financial support, whilst not 'blowing the budget'; and how to restructure paid work so that men's and women's caring tasks can be handled with less difficulty.

Another answer often given is that caring is a private family matter, and only in extreme cases should families expect others to take over and/or assist. As the paper has argued, this is an absurd view of how society operates and is historically myopic. No family survives alone, especially not the 'nuclear' family of today. Schools, hospitals, public transport are all there because the so-called 'autonomous' family cannot do it all alone. Is caring any more personal than health care or developing a child's mind? Both health and education are shared by the family and public provision. Why not other forms of care? It is not being proposed here that public service provision 'take over' from family care; rather that a better balance be struck. Caring is a community responsibility.

A third dilemma is how best to distribute scarce resources between carers and the cared for. Whose interests are being served, whose 'rights' to assistance are paramount? In my view, this is a false dichotomy. It is very hard to separate support for carers from that for carees, since both groups benefit from any support. But it does seem clear that programs aimed only at the dependent person will miss much of the context in which he/she lives. Indeed with severely handicapped or intellectually disabled people they can only respond through the views of and support for their carers. Targeting carers and building a supportive community around them must be good for those cared for. It also recognises the special burden carers carry and their right to recognition and support from the society which benefits from their work.

Some might also claim it is counter-productive to say others should share the caring role. Women 'want' to care,

are 'best' at it, and caring must be done by someone. Don't we want women to care? The answer is, of course, to ask: Why only women? Why does the language of care have to translate into such gender-specific pressures? Why can't the language (and the task distribution) be changed?

We must begin to ask, 'How do we ensure the best of care but not destroy the carer?' (OWN 1992).

More lateral thinking about community support for the caring task is essential. This will involve planning across government departments and agencies, between the State and private business, between families and work, between families and school, linking education and socialisation processes with the practicalities of housing, public transport, urban design, hostels and varied forms of respite care. Some suggestions for that cross-linking in support of carers are offered for wider discussion.

Community supports for carers

A key problem for those who care seems to be their isolation and lack of recognition. Caring for persons with severe physical or intellectual disabilities is very time-consuming and sacrificing of self. Such carers need to be given windows of opportunity for self-expression and contacts with other carers who understand and share their feelings. The HACC program has made a good start in this direction, but it is just a start.

That is why respite care arrangements are so important and why consultations and networking with carers can be so supportive. The work of Women's Councils has been most effective. The WAC initiative in Western Australia provided the State Government with crucial information and recommendations to support carers. The Tasmanian Women's Consultative Council is also soon to report to the Premier on the needs of women as carers. The New South Wales Women's Advisory Council is carrying out consultations looking at the health status of women carers in Marrickville, Sydney, which has a high percentage of migrants and families from non-English-speaking backgrounds. They will be targeting the Vietnamese and Greek communities with bilingual interviews — exactly the sort of information needed about a group of carers little is known about.

Several Western Australian initiatives offer family support in ways which help 'share the care'. The Authority for Intellectually Handicapped delivers a family support program which recognises the needs of carers of such children at all ages, even after they become adults. The ACTIV Foundation operates a number of parent and family support services, including respite care, camps for parents and siblings.

In line with our central theme that all people, male and female, young and old, need to share in the care ethic of a truly civil society, we all need appropriate outlets for expressing it. In North America and elsewhere, a proliferation of inter-generational programs offer such outlets. Young and old can work together, as in the Ageing Society Project of the Carnegie Foundation for Child Development. New models, such as developing day care centres for children in nursing homes for the elderly, provide benefits to children, to their parents, and to nursing home residents (Kingson 1989).

Rigid bureaucratic separation of service programs and funding processes works against this more inclusive social

model of care. We set up youth programs, child care, aged and disability services which exacerbate isolation, group segregation and misunderstanding, and thus miss the best opportunities to offer care and create a more caring society. A true model of 'community care' would share skills, funds and people resources, with co-location of different age groups and care services in regular local meeting places.

New untapped resources for caring services should be drawn upon. This includes both youth, who need 'work experience' in human service interaction; and our active 'elders' whose skills, energy and experience could be utilised more fully in inter-generational programs to enhance the quality of community and family life.

New models of volunteerism could be developed, so that care and support freely given, might be linked with training in the human services and graduated rates of pay as experience and qualifications increase. The civil society is not one in which everyone is paid for everything they do for others; but it is one in which essential skills are nurtured and recognised.

Housing

One aspect of community support is the need to link policies of care with other aspects of social policy. This is nowhere better illustrated than in the area of housing. Housing issues are fundamental to community care and new models of shared living should be explored.

Housing policy must be forward-looking about the elderly and others in need of prolonged care. Crowding, lack of personal space can cause tension not just for the dependent person but for the caring family as well. Moving in with a daughter, or having the family move in with them can both cause a loss of status and exacerbate tensions over time.

The evidence is that most of the elderly would prefer to live alone, or with others who are not family members, as long as health allows. Older people sharing a house or unit may live as 'family', sharing services more efficiently and still getting emotional and other support from their own kin. But other network needs could still be met with more imagination (Earle 1992).

Some scepticism is required about schemes to re-mortgage an old person's home to cover living and health or other service expenses. In theory, such 'assets' are advantages over the ageing poor, but converting it to disposable income depletes the asset, removes security and reduces those inter-generational transfers that make for family viability rather than welfare dependency further down the line. A more active assistance/advisory scheme to convert one-person households into income-generating *share care households* would seem more sensible, preserving assets, generating income, creating social family substitutes and enabling more efficient home help and service delivery.

In Sydney, a small but particularly innovative organisation — Housing Options for Older Women (HOOW) — has formed a self-help group to examine housing choices. Their options include models which could be self-contained, co-operative, shared, supportive with communal space but still allowing for independent living. They are probing the practical and legal problems associated with such choice. The message here is the need to clean the cobwebs out of our thinking about institutional care versus nuclear family

arrangements and look to developing new, improved models of shared living arrangements which can be much more promising than they often recognise. Older women can do much to support each other with housing and care needs. Wider support for groups such as HOOW would boost their limited resources and enable them to move more quickly and easily towards transforming well thought out options into living realities (OWN 1992:15).

Related to housing and the needs of carers is the whole area of urban and rural planning. Both public transport and private bus services could be better designed to assist people taking carers to medical centres, recreation places, respite care locations. Contact by radio/telephone, the issue of 'beepers' to carers and carees for use at times of emergency would add to their sense of security and reduce the necessity for actual visits. Such beepers could be linked to homes, workplaces, a central mobile check-up service. Shopping centres now have child-care facilities; why not meeting places for carers, rest places, video centres for those being taken on outings? Variety and ease of access to support services, designed to assist particular care needs are the key.

Research needs

There is a dearth of Australian research that documents the varied needs and coping strategies of carers and evaluates the effectiveness of current support programs. Women of different ages, income and education levels, cultural and ethnic groups may not require the same sorts of support. Men who are carers are a missing group. The way to deliver carer support in rural and remote areas, in Aboriginal communities, in outer and inner suburbs will have different profiles.

The type of dependency and the age of the person cared for will alter their needs and what their carers require to survive. Younger accident victims, AIDS patients, the hearing or vision impaired will demand different care from their carers than older people do. We do not know enough to develop responsive models for all these groups. Nor do we know how the caring task affects those other family members who have to live with a major caring relationship.

Particular attention needs to be paid to 'transitional' periods of caring; when, for example, a child with a disability reaches age 16 and needs some introduction to employment and specifically targeted vocational training. Or when a young adult makes the transition from home care perhaps to independent or group living, how is the carer affected, and how can she be assisted in making her own transition out of the full-time caring role? Shorter-term 'transitions' also need attention, such as when schools or sheltered workshops close at the end of the year and mothers are looking for other options and activities for their children. Long-term care plans need to anticipate the obvious life-cycle transitions and offer professional help.

Consultations with carers are crucial if such 'research' is to be useful. Large surveys may be less revealing than carefully focused discussions with groups of carers (as in the WA consultations), or detailed case-studies of how carers are dealt with by existing support programs and how they deal with caring and transition tasks.

The ethnic aged need special attention. Language train-

ing, or at least translator services are vital if they are ill and need to access services. The family may not be able to reach out in traditional ways, so the host society has a responsibility to reach out, provide public transport, media services in their own language, help create new networks for ethnic women who are displaced in old age. It is not just a matter of the Greek or Vietnamese community taking responsibility for 'its own' — concern and care needs to involve many systems, the family, the culture, the community and the (often unrecognised) skills of the individual person.

Empowerment

Above all, we must cease talking in terms of caring for, and more about working *with* such people. The language tends to take away their personhood, assume they are passive and have no will or capacity to live their own way. The aged are not children, nor are the older disabled. We talk of caring for instead of allowing them the power to make their own decisions, often without the realisation that it is often the old person who is *doing* the caring as well — for a spouse, for a child or grandchild, and for themselves. Both those cared for and their carers must be given the chance to construct flexible care arrangements that suit their joint needs rather than being expected to fit into a 'system' provided top-down. As an example, the concept of the 'Third Age' has caught on. Other groups such as WOW (Wise Old Women) offer value terms that assert the positive growth elements of ageing. (We could add WOM Wise Old Men as well). Ageing is not like a second childhood; other life transitions have been completed and new, not old, things happen as we age. We must also recognise the diversity of old age and disability (Neugarten, Kingson) and not assume that people have the same interests or needs for care. The many self-help groups in existence need to be given greater recognition and funding support.

Carers' groups such as The Carers' Council of WA, WA Carers' Network (WACOTA), the Red Cross Carers' Group, and the Alzheimer's Association offer information and other assistance to carers. Parent support groups such as Pledg (Parent Learning Education Development Group); The Carers (Home Care Service); WA Network Community Based Home Support; and The Support Group, Parents of Children with Disabilities (Inc); all work to inform parents and other carers, offering advice on survival and stress management. A family empowerment program is being planned to improve parent effectiveness and ensure better coping strategies.

Community care options should, in such ways, maximise the contributions of the cared for themselves. Let them help in the planning, in the brainstorming. It is absurd to think, for example, that an elderly woman who has spent her life juggling roles, running a household economy and a complex social group called 'the family', suddenly loses her voice, or her sense of options. We should use her (and his) understanding and skills in planning new models for care. Indeed, this could be a first research project to follow from this report: a series of planning discussions with 'those cared for' to see what alternatives they might suggest.

We might consider developing an Australian equivalent of the US 'Silver Manpower Centres', but be less sexist and

call them 'Silver Resource Centres'. The Western Australian 'Beehive Industries' is an example. These would act as a clearinghouse for elders who want to assist, to act as mentors in a learning exchange way, or work part-time after retirement. They could be drop-in centres for youth and younger families seeking advice on anything from job applications, to gardening, to setting up a business, to dealing with a difficult care situation. Preferably they would be linked closely to the community, schools and workplace, to more structured settings that could expand the range of resources available. They might even be funded directly by the new CARE program which would replace HACC to act as peer-level 'brokers' assisting the aged and disabled and their families to negotiate a range of services and supports that encourage independence and hope rather than a 'You've had it, and we know what's best for you' mentality.

Another form of empowerment is the promotion of more positive attitudes to health and fitness. While there will always be the frail and the severely disabled, research has shown exercise and diet can improve physical and mental wellbeing at any age. Carers can benefit by their own fitness and that of those cared for. The Western Australian Health Promotion Foundation's 'Healthway' scheme, like Vic Health, directs part of the State's tobacco tax towards healthy outcomes. Projects include replacing advertisements in sports, arts and racing with health messages (such as 'If old age is catching up, walk a little faster!') and also support for research and service development for carers and community groups: for example, the Noongar Alcohol and Substance Abuse Services; the Joondalup Community Trust; the Community Diabetes Health Promotion Program in WA; or the Men Only Cook Days and Older Women's Health Promotion projects in Victoria.

It should be clear that policies which encourage continued independence are already making a positive contribution, but the changing nature of women's labour force participation demands more support for the carers of even relatively healthy and independent elders and those with special needs.

Employers and care

Work structures will obviously be important in shifting the balance of care and should not be ignored in policy considerations.

The competing economies of the household and the market mean a loss of productivity and quality of life in both. Carers must be supported not just through the home or via community-based services. They need to be resourced through the structures of work as well, which means that social policies about care have to be closely linked to social policies about work. The Australian government's ratification of ILO 156 on Workers with Family Responsibilities suggests the need for rethinking our whole approach to care. If we remember that caring for others is an integral part of life, in fact that work itself is engaged in for the purpose of ensuring adequate care of others important in our family lives, then perhaps we will develop work policies that make it more possible for people to carry out their caring roles as well as their income-generating roles (Miller 1991).

This does not mean employers have to act as substitute carers. But they must recognise that virtually every employee is a carer — of young children, teenagers, partners

and parents — and that work demands can make that caring job easier or more difficult. Companies that do consider the family responsibilities of their workers, reap rewards in better morale and productivity, reduced absenteeism, accidents and job turnover (Wolcott 1991; Galinsky, Friedman and Hernandez 1991).

Some honest rethinking is also needed in relation to child care policies as these affect women at different class levels and as they affect other caring responsibilities. Women of middle and upper classes have better paid jobs and access to resources which enable them to buy services not as easily available to women with less income. Commonwealth priority of access is given to women entering the labour force and studies have shown that the major users of child care are middle class, often two-income families (Sweeney 1987). Women of lower classes are less likely to find adequately paid employment, are often subject to social security poverty traps and more likely to find themselves caring for wealthier women's children. These disadvantaged women are thus more likely to suffer the stresses of caring for their own and others' children, disabled spouses and aged parents. Overseas models, such as that of Finland, offer real alternatives of continued pay while on leave caring for children or work with full access to quality local child care.

Those who are not in paid employment may not benefit directly from such reforms but changes in the workplace are central to a more caring society. Unemployed carers whose partners are employed would certainly benefit if leave arrangements, work times, employer-provided information/counselling/referral systems were made available.

New family roles

The way in which families allocate the caring and income-earning tasks is crucial. The early socialisation of boys and girls is the starting point of sexism so parent education, the 'hidden curriculum' of pre-schools, schools and the media in the treatment of gender differences, the role models set by mothers and fathers about care need to be addressed.

Writers such as Reibstein and Richards (1992) argue that the basic necessity for boys to 'separate' from the mother as the key caring figure leads to a segmentation of male emotions from their behaviour. Their suggested 'solution' is for more active and emotional involvement by and with fathers so that care and affection can be identified with masculinity and not segmented. One might not agree with the Freudian overtones of this theory, but the significance of fathers in setting an agenda for caring attitudes is obviously strong. The UN Declaration on the Rights of the Child fails to mention the word 'father' but the International Council of Women has begun to redress that omission in preparations for the UN Year of the Family 1994 (Edgar 1992).

Education about caring for (rather than just about) others has to start early but it can also change attitudes later on in life. Public education campaigns targeted at employers and employees in the workplace, men in sporting and drinking places can be effective. The role of Western Australia's 'Family Centres', located in neighbourhood shopping centres and local schools has the potential to demonstrate people's inter-dependence and how inter-generational linkages can operate to remove the isolation of both carers and those cared for.

The social caring model

Finally, let me restate the 'utopian' vision of social care on which this paper has been based.

A social caring model must permeate the entire community. This will require a much firmer understanding of inter-generational responsibilities and the role of the community in providing caring support. A carer is not just a full time carer, indeed both men and women phase in and out of caring responsibilities throughout the life cycle. Inter-dependency is a fact of life, and everyone is a carer in some way or another, more or less active at certain times.

A truly social care model would recognise that care of vulnerable persons is not just a family responsibility but rather that public services must be made available to people who need them as part of a social security system based on the rights of citizenship (Neysmith 1991). The aim should be to provide support that enables carers and those cared for to thrive rather than merely to cope. A residual view of social welfare, that is that services are set up to fill in gaps when the preferred model of family care breaks down, needs to be replaced by a social model of care in which universalistic services are made available to meet the particular needs of clients and carers as a basic right of citizenship.

Our model of community care must not be based on an economic rationalism that puts the system above the people it is meant to serve, but should be based instead on an economic humanism (Edgar 1991a) which reasserts the primacy of civil society, the centrality of family, neighbourhood, culture and individual choice-making within an active social structure. Social policy should be seen as integral to any effective economic policy.

In such a model, investment in human capital, human capacities to cope individually and collectively with our varied environments would become the language of discourse to replace the exploitative market rationale. The impact of policies and programs on human beings, not their efficiency or cost-benefits alone, would become the key 'performance measures' of society. Every individual would be valued and valuable, responsible for and contributing to the well-being of others. A new language about the 'aged' would offer respect to our 'elders', chances for them to lead an active and healthy life, recognise their potential as resources to the whole community and start building inter-generational linkages to break the arbitrary age-grading of society (Bowers 1987; Braithwaite 1990; Edgar 1989, 1991b; Earle 1992).

The work system would be restructured to ensure flexibility and reduced stress in coping with the dual responsibilities of work and family (Dey et al 1991; Pearlin et al 1990). Youth would be reincorporated into the mainstream of society, with active community service work by them as a core part of the 'curriculum' and recognised as real work experience. The war on poverty would be geared up so that families and dependent individuals had the resources to bargain for the care supports they need, to be active brokers in their own interests. And more creative approaches to the housing mix, the design of urban living, the local delivery of services and the tax and welfare mix would ensure the proper integration of carers and cared for in a truly civilised society.

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